



Palliative Care Awareness in Iowa

A report from the Patient-Centered Health Advisory Council in response to House File 393

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Executive Summary

The Iowa Department of Public Health's Patient-Centered Health Advisory Council has conducted a survey to assess the public's awareness of palliative care, and has developed a set of recommendations aimed at increasing awareness and reducing the barriers to accessing palliative care. The council recognizes that these recommendations are long-term goals and will require collaboration with multiple components of the health care system to be successfully implemented. The council believes much of this work can be incorporated into the scope of existing organizational infrastructures with shared goals, priorities and outcomes related to improving palliative care in Iowa. To successfully implement this shared mission, contributing stakeholders should agree to coordinate the palliative care activities that fit within their professional scope.

Recommendations

Continuation of Palliative Care Work

1. Identify an organization that has expertise and is currently working on palliative care to coordinate stakeholders and palliative care efforts in Iowa.
2. Develop or adopt an Iowa definition of palliative care.
3. Develop platform(s) to serve as a clearinghouse in Iowa for palliative care resources and information.

Education and Awareness

4. Increase education to the public about advanced care planning and palliative care.
 - Conduct a multifaceted outreach campaign focusing on what palliative care is and that clearly differentiates it from hospice care.
5. Incorporate education to the healthcare sector, including the healthcare team.
 - Incorporate person-centered palliative care education into healthcare professional curriculums and other appropriate educational settings.
 - Offer palliative care trainings and technical assistance in healthcare settings across Iowa.
6. Integrate palliative care throughout the healthcare system by incorporating palliative care discussions into different healthcare settings, including primary care, specialty care and integrated health teams, so that it becomes common practice.
7. Provide educational resources for primary care, specialty care, integrated health teams and the public to increase the use of advanced care planning and palliative care.

Surveillance and Assessment

8. Determine and monitor where palliative care specialty services are available in Iowa, including what specific palliative care services are being provided and identify shortage areas.

Best Practices and Research

9. Increase the recognition and adoption of national tools, resources and best practices in palliative care and advanced care planning.
10. Identify best practice referral methodologies for providers to refer patients and their families for palliative care specialty services.
11. Ensure that palliative care and advanced care planning services are culturally and linguistically appropriate and accessible to all.

Reimbursement

12. Explore and identify reimbursement methodologies in order to integrate and support palliative care and advanced care planning in all appropriate care settings.
13. Educate healthcare leaders, stakeholders, payers and policymakers on the evidence for improved outcomes and cost-savings from providing palliative care.

Workforce Development

14. Identify palliative care workforce gaps and barriers and explore strategies to increase the palliative care workforce, which includes supportive and home-based services.
15. Identify best practices to encourage and incentivize educational institutions, health care delivery systems and professional organizations to increase the number of palliative care specialists in Iowa.
16. Engage and integrate allied professionals and community services in the collaborative provision of person-centered and palliative care.

Utilization of Advanced Care Planning

17. Promote early and routine person-centered advanced care planning across all settings, including family members, caregivers and durable powers of attorney as appropriate.
18. Enhance awareness and utilization of methods to document patient care wishes such as living wills, advanced directives and the Iowa Physician Orders for Scope of Treatment (IPOST).

Introduction

House File 393ⁱ was signed in May of 2017 and charged the Iowa Department of Public Health's Patient-Centered Health Advisory Council to review the public's awareness of palliative care and provide recommendations to increase awareness and reduce barriers to access palliative care services. Appendix A gives an overview of the Patient-Centered Health Advisory Council and lists the members. The language from House File 393 reads as follows:

The Patient-Centered Health Advisory Council shall review the current level of public awareness regarding the availability of palliative care services in the state and shall submit a report to the governor and the general assembly by December 31, 2017, including the Council's findings and recommendations to increase public awareness and reduce barriers to access palliative care services throughout the state.

Since House File 393 was signed in May 2017, the Patient-Centered Health Advisory Council brought together palliative care stakeholders from across Iowa to learn more about the field and to discuss the benefits and barriers to receiving palliative care. A palliative care physician from Broadlawns Medical Center, Dr. Yogesh Shah, joined the council and offers valuable experience and expertise. The Council also conducted a survey to gauge the public's awareness of palliative care and has developed a set of recommendations.

The online survey was distributed to a large audience, including many professional organizations and numerous distribution lists. Additionally, the survey was posted on the department's Facebook page, Twitter, Pinterest, and the website homepage. Survey questions were adapted from similar studies done in other countries, including Irelandⁱⁱ and Scotlandⁱⁱⁱ. The survey was piloted internally at the department prior to being widely distributed. A total of 590 responses were received from July 18, 2017 to October 9, 2017. Each respondent answered all of the survey questions.

What is Palliative Care?

Palliative care, also known as supportive care, is specialized medical care for people living with a serious illness. It focuses on managing the symptoms of serious illness or life-limiting condition, such as pain, nausea and fatigue. Palliative care programs also provide an extra layer of support for practical needs, particularly for care provided at the patient's home. The goal is to improve the quality of life for both the patient and the family.

Palliative care is optimally provided by a team of experts (palliative care physicians, nurses, social workers, hospice and palliative care aids, and others) who work together with the primary specialist treating the patient for their specific illness to provide an extra layer of support. It is appropriate at any age and at any stage of a serious illness, and can be provided at the same time as medical treatment. Palliative care is also a philosophy of care to optimize patient comfort. Where a fully developed team is not available, the principles of palliative care can and should still be incorporated into the plan of medical care for appropriate individuals by their treating providers.

Key elements of person-centered palliative care include the following:^{iv}

- Relieves symptoms, pain and stress of a serious illness—whatever the diagnosis;
- Facilitates communication with patients for advanced care planning about patient care goals and provides support for complex medical decision-making;
- Improves quality of life for both the patient and the family;
- Is optimally provided by a team of doctors, nurses, social workers, chaplains and other specialists (e.g., psychologists, pharmacists, physical therapists, occupational therapists, music therapists, etc.) who provide an extra layer of support in conjunction with all other appropriate medical treatments, including curative and life-prolonging therapies and may include community services; and
- Is appropriate at any age and at any stage in a serious illness.

Numerous studies demonstrate that palliative care significantly improves patient quality of life and symptom control. Additionally, integrating palliative care into the care of those who have a serious illness (particularly the top 5 to 10 percent of patients who account for approximately 50 percent of spending) in the U.S. can improve the quality of care delivered. Palliative care results in fewer symptom crises, which reduces unnecessary utilization and bends the cost curve. This is beneficial for consumers, providers and payers.^v

A 2011 study published in Health Affairs demonstrated that hospital based palliative care teams create efficiencies that deliver significant cost savings. Provision of palliative care consultations to Medicaid patients at four New York state hospitals resulted in almost \$7,000 of savings in hospital costs per admission and these patients spent less time in intensive care and were less likely to die in the intensive care unit. The study's estimated reduction in New York Medicaid hospital spending, if all large hospitals were to have a palliative care team, was between \$84 and \$252 million per year.^{vi}

Patient Stories

Broadlawns Medical Center Palliative Care Program

“Arnold” was diagnosed with end-stage liver failure and end-stage COPD two years ago. He had significant chronic pain. He and his wife, “Mary,” would visit different medical settings to manage his symptoms. Most of their days would be filled with visits to urgent care, the emergency room and outpatient clinics, making their quality of life very poor. He would get admitted at least once every other month to manage his symptoms. Mary had her own chronic medical issues and felt overwhelmed coordinating her own care and while taking care of Arnold. During one clinic visit with her primary care provider, Mary finally broke down and started crying and expressed that she could not take care of him anymore.

Luckily for them, Broadlawns Medical Center had started its palliative care program at the same time and Arnold became one of the first patients. The palliative care team took them both under its wings and became very close, providing significant social and emotional support. Instead of going to the emergency room for symptom management, Arnold would regularly visit the palliative care clinic. His symptoms were minimized and his quality of life improved. He was able to decide short-term and long-term goals for him and his family. His goals ranged from visiting his mother who lived only 30 minutes south of Des Moines for the first time in two years, to reconnecting with his 20-year-old son after many years. Arnold and Mary enjoyed six months of quality life together and he passed away at Broadlawns Medical Center surrounded by his extended family, friends and even his cat. The team continued to keep in touch with Mary and enjoyed sharing stories about Arnold’s life.

University of Iowa Stead Family Children’s Hospital Pediatric Pain and Palliative Care Program

“Justine” was diagnosed with advanced stage chronic renal failure as a teenager. She had already faced many serious medical issues in her life. The path of dialysis and renal transplant that would normally have been considered at her age was not a good fit based on her other medical problems. Palliative care helped Justine, her family, and the other medical specialty teams navigate the way ahead. Care conferences with the family and healthcare team helped identify Justine and her family’s goals and priorities for her life. This allowed for development of a treatment plan that helped her live as long as possible, as well as possible. She wanted to spend time at home and school, so multiple specialties coordinated schedules to minimize time spent at the hospital. The palliative care team helped the family weigh the potential benefits and risks of various treatments, and focus on those that were most consistent with her overall goals.

Justine was able to participate in important events with her peers, including going to prom. She went on a Make-A-Wish trip to see her favorite sports team and met some of the players. The social worker helped get additional nursing care and equipment when needed, so that Justine could remain at home, even during times when she needed intravenous medications. Nursing checked in by phone on symptoms regularly, so that adjustments could be made in medications that kept her more comfortable and functional. During a short admission to the hospital, the child life specialist and music therapist helped her make a special video for her family as a Christmas present. The art therapist gave her opportunities for creative expression that became lasting mementos for her friends and family. The chaplain helped Justine and her family explore their concerns and hopes about the dying process in a way that eventually brought them a sense of peace and acceptance. As her renal failure worsened and symptoms became less manageable, Justine enrolled in concurrent care hospice. This allowed Justine and her family to receive support for her care at home and in the community, while also continuing specialty care from the children’s hospital. After several years of palliative care support and several months with hospice support, Justine died at home. Her parents and sibling received bereavement support from both hospice and the children’s hospital grief services program. They were grateful to have had the best possible support for Justine’s journey, and have continued to be strong advocates for early palliative care involvement.

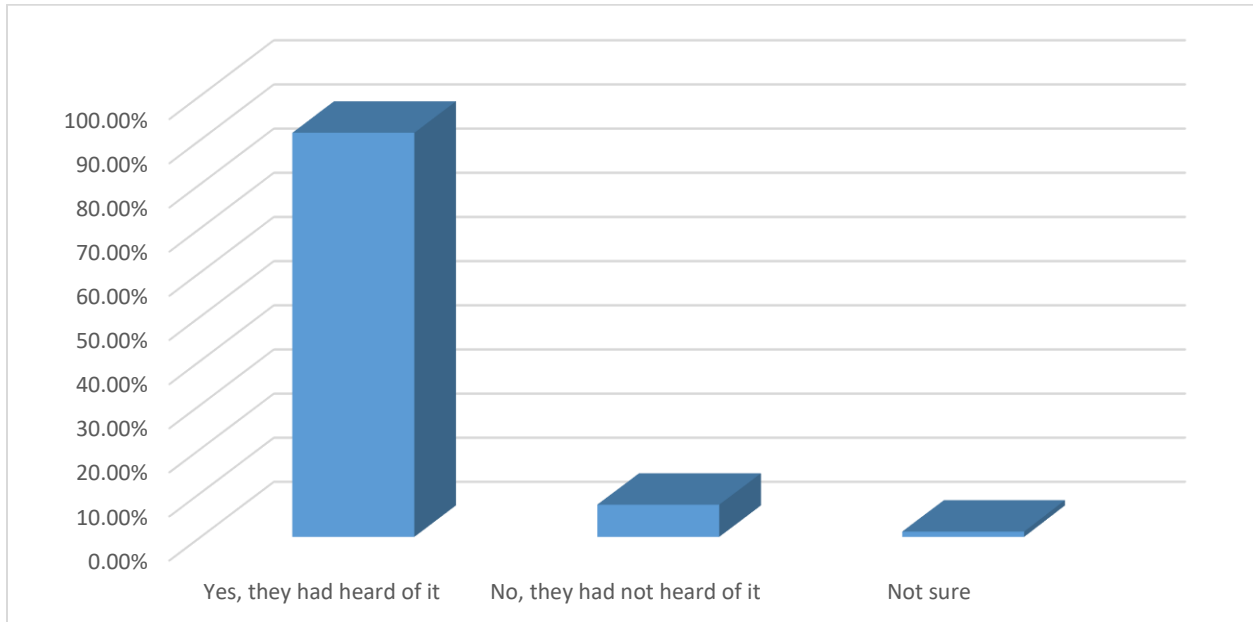
Survey Results: Palliative Care Awareness in Iowa

Below are the results of the 10-question Palliative Care Awareness Survey conducted electronically via SurveyMonkey. A total of 590 responses were received from July 18, 2017 to October 9, 2017. Each respondent answered all of the survey questions. See Appendix B for the survey questions.

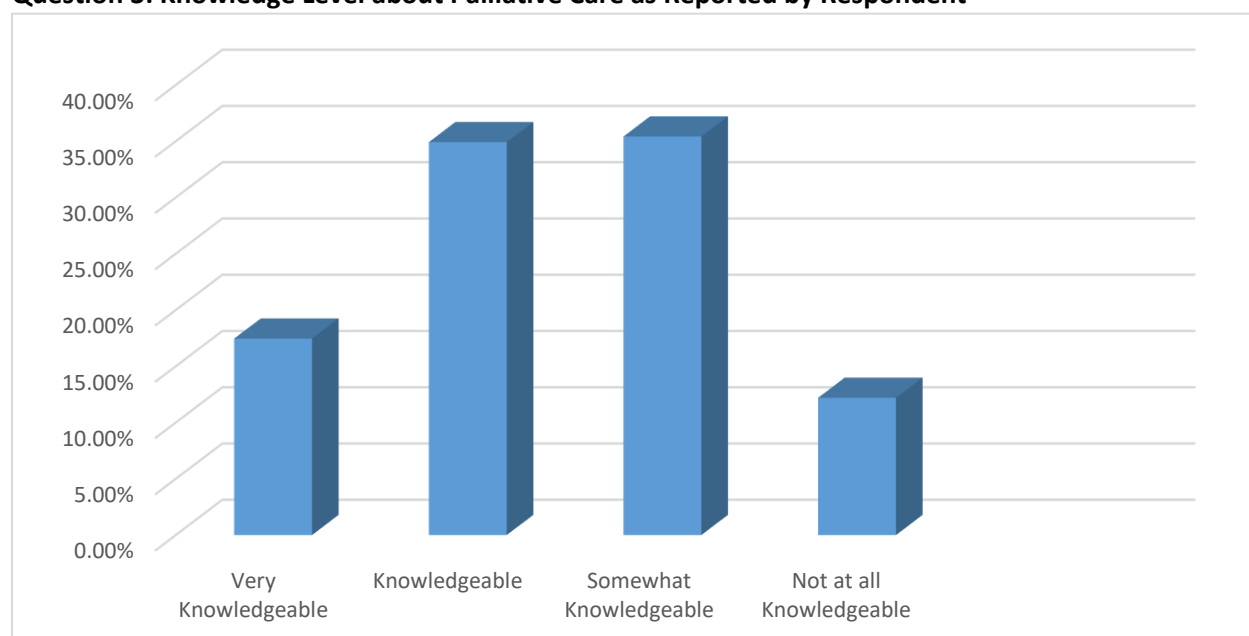
Question 1: Demographics of Survey Respondents

Answer Choices	Responses
Health Care Provider Not Working in Palliative Care	24.92%
Health/Social Service Professional	20.85%
General Public	18.47%
Family Member/Caretaker	14.41%
Health Care Provider Working in Palliative Care	9.66%
Other	7.12%
Consumer/Patient	4.58%

Question 2: Respondents Who Had Heard of the Term Palliative Care



Question 3: Knowledge Level about Palliative Care as Reported by Respondent



Question 4: Respondents who know Where to Access Palliative Care

Answer Choices	Responses
Yes, they would know where to access it	62.71%
No, they would not know where to access it	37.29%

Question 5: What Respondents think Palliative Care Tries to Achieve

Answer Choices	Responses
Comfort	90.17%
Quality of Life	86.27%
Pain Relief	86.10%
Dignity	80.85%
Support of caregivers	75.25%
Care before death	67.12%
Peaceful death	57.46%
Not Sure	5.25%
Other	4.24%

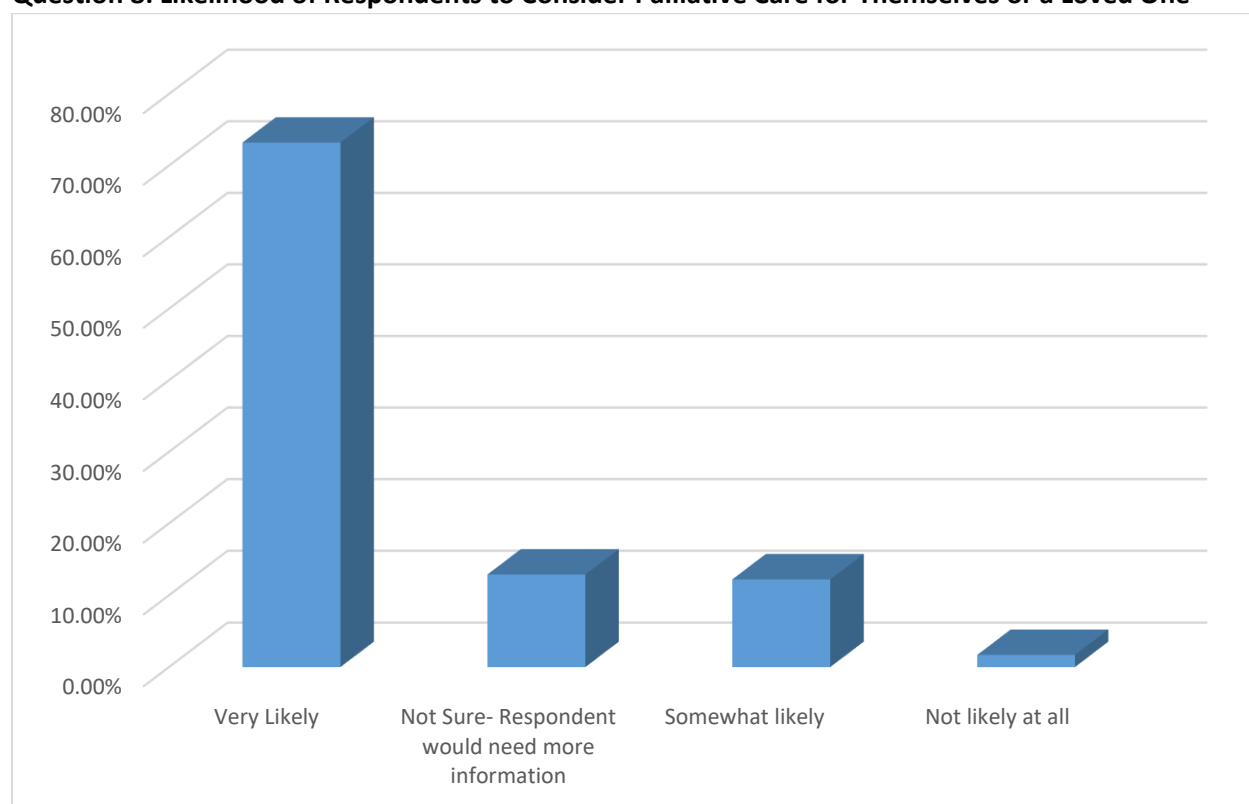
Question 6: Where Respondents Think People Currently Receive Palliative Care

Answer Choices	Responses
Own Home	83.39%
Hospice	72.54%
Nursing Home	70.17%
Hospital	65.42%
Not Sure	8.64%
Other	4.92%

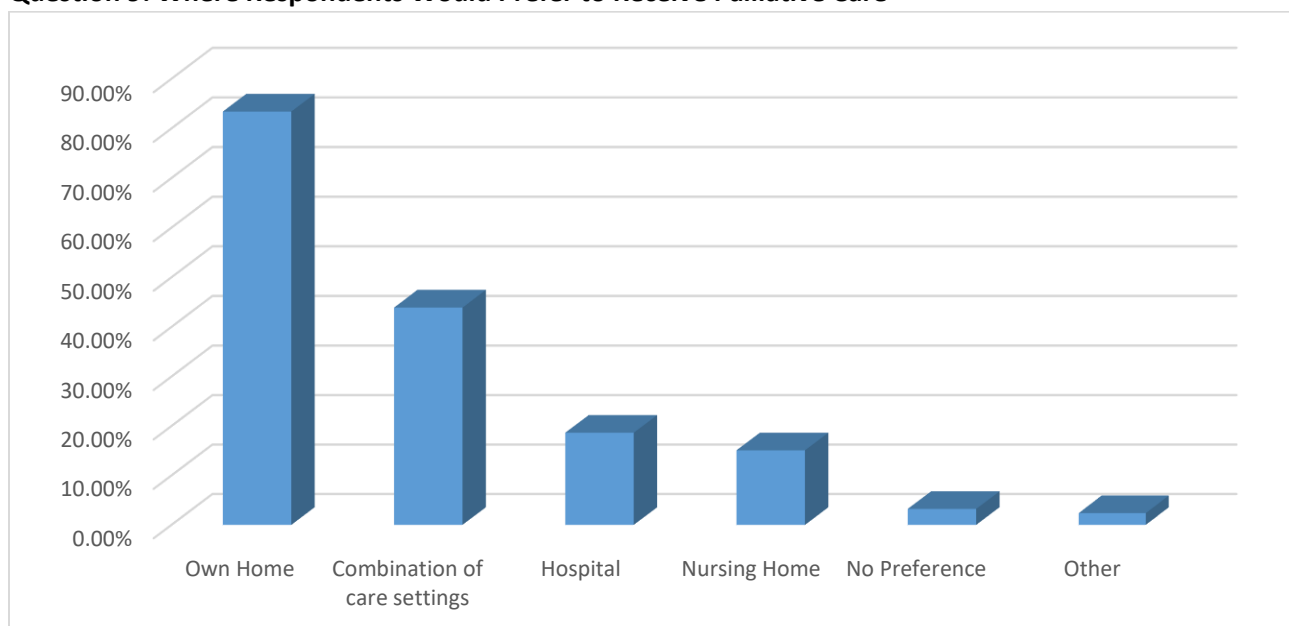
Question 7: Services that Respondents Think Palliative Care Should Include or Provide

Answer Choices	Responses
Control of pain and other symptoms at home	94.58%
Methods of comfort	91.19%
Extra Help at home to give family caregivers support	84.24%
Someone to be available by the phone for support	81.36%
Alternative therapies such as aromatherapies, reflexology, meditation, acupuncture	74.24%
Nursing help at home during the day	67.80%
Nursing help at home during the night	63.05%
Someone to talk about spiritual matters	61.02%
Medical care in a hospice	56.95%
Medical care in a hospital	49.83
Information and advice on financial matters	47.12%
Help at home with housework	37.63%
Other	5.76%

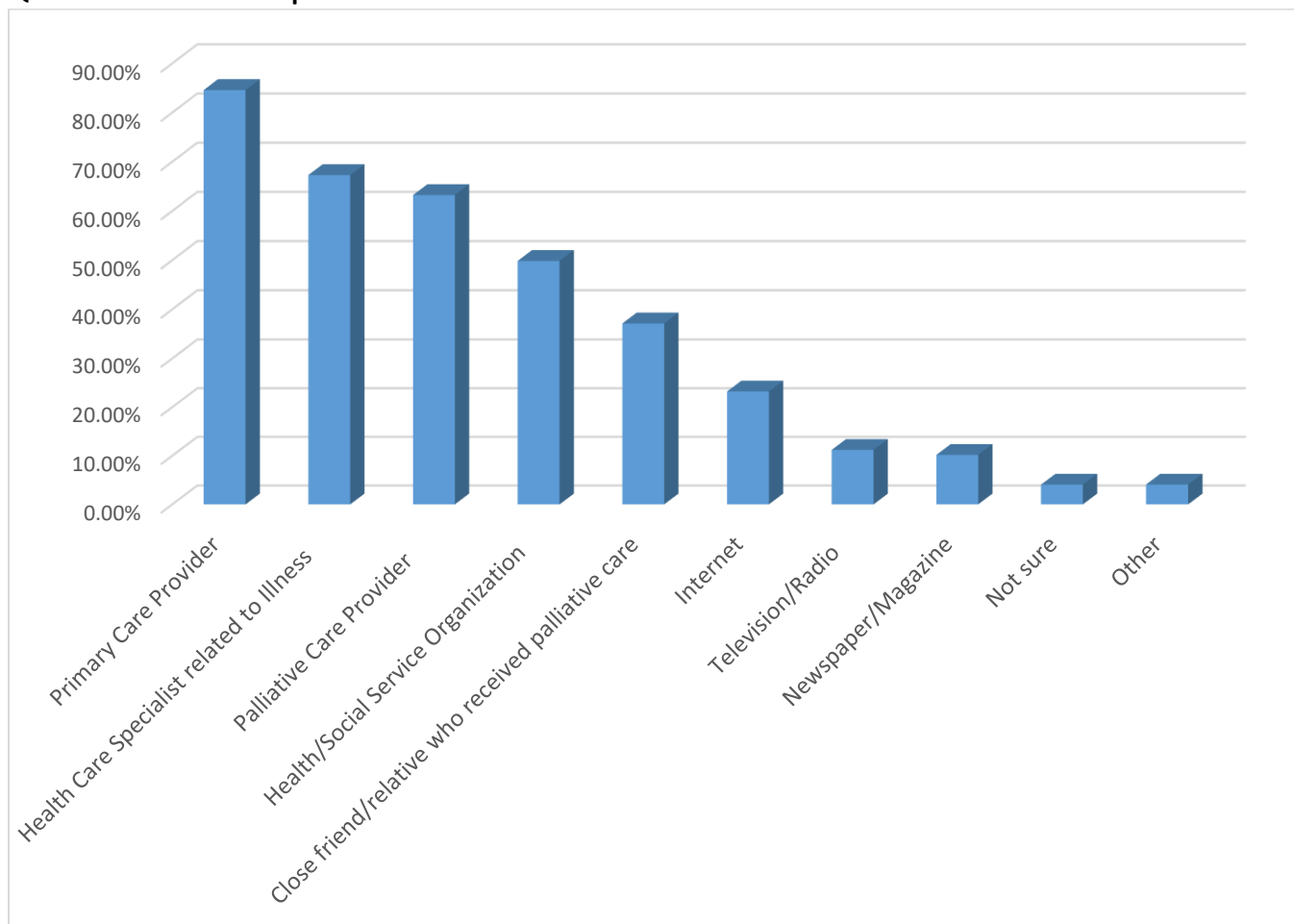
Question 8: Likelihood of Respondents to Consider Palliative Care for Themselves or a Loved One



Question 9: Where Respondents Would Prefer to Receive Palliative Care



Question 10: Where Respondents Would Prefer to Receive Information about Palliative Care



Recommendations

Numerous studies show that palliative care improves quality of life and controls symptoms of serious illnesses such as pain, fatigue, anxiety, nausea and depression. The council recognizes the extensive benefits of palliative care and has developed recommendations to increase public awareness and reduce barriers to access palliative care services throughout the state. The council endorses the following 18 recommendations around the continuation of palliative care work, education and awareness, surveillance and assessment, best practices and research, reimbursement, workforce development and utilization of advanced care planning.

Continuation of Palliative Care Work

Ongoing work should include the identification of which stakeholder group would best lead the implementation of each recommendation. For example, the healthcare provider community would probably be the most appropriate in leading efforts in raising awareness and promoting palliative care in the healthcare sector.

The palliative care awareness survey shows that 85 percent of respondents would consider palliative care for themselves or a loved one.

An organization in Iowa that has experience and is currently working on advancing palliative care in the state would be well-suited to lead palliative care efforts. The palliative care awareness survey shows that 85 percent of respondents would consider palliative care for themselves or a loved one.

Additionally, almost 40 percent of respondents would not know where to go to access palliative care in Iowa.

Additionally, almost 40 percent of respondents would not know where to go to access palliative care in Iowa. **This shows that there is a need for increased education, awareness and access to palliative care in the state, and that this work is important and needs to be continued.**

Developing or adopting a consistent definition of palliative care is a very important component to expanding public education and awareness. Palliative care is becoming more widely incorporated into a variety of healthcare settings and with a variety of serious illnesses. A consistent definition will ensure that the public and the healthcare sector recognize and understand the goals and purpose of palliative care. It is important to clearly distinguish that palliative care goes beyond hospice care and that it is appropriate at any stage in a serious illness.

The Center to Advance Palliative Care (CAPC), a leading resource for palliative care development and growth, defines palliative care as:

Palliative care, and the medical sub-specialty of palliative medicine, is specialized medical care for people living with serious illness. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

The Patient-Centered Health Advisory Council recommends the following related to the continuation of palliative care work:

Recommendation 1:

Identify an organization that has expertise and is currently working on palliative care to coordinate stakeholders and palliative care efforts in Iowa.

Recommendation 2:

Develop or adopt an Iowa definition of palliative care.

Recommendation 3:

Develop platform(s) to serve as a clearinghouse in Iowa for palliative care resources and information.

Education and Awareness

Palliative care has been increasing in availability, in part due to new value-based care incentives that promote an environment in which payment relies on not only treating the illness, but keeping patients comfortable and, when possible, at home. As palliative care becomes more common, it is clear there is a significant misunderstanding about palliative care among patients as well as providers. Many mistake palliative care for hospice care, which is focused on end-of-life care. This misunderstanding illustrates the need for public education and awareness about palliative care.

Palliative care is about symptom management, which can be beneficial at any point in an illness. It can be delivered to anyone with a serious or chronic medical condition from the time of diagnosis, regardless of whether the patient is terminally ill, expected to recover fully, or facing years of chronic or progressive disease. Palliative care can be provided at the same time as curative medical treatment to help patients tolerate side effects of treatment, while carrying on with everyday life. This includes social, emotional and spiritual support, as well as advising families on how to care for their loved ones.^{vii}

Recommendation 4:

Increase education to the public about advanced care planning and palliative care.

- Conduct a multifaceted outreach campaign focusing on what palliative care is and that clearly differentiates it from hospice care.

Recommendation 5:

Incorporate education to the healthcare sector, including the healthcare team.

- Incorporate person-centered palliative care education into healthcare professional curriculums and other appropriate educational settings.
- Offer palliative care trainings and technical assistance in healthcare settings across Iowa.

Recommendation 6:

Integrate palliative care throughout the healthcare system by incorporating palliative care discussions into different healthcare settings, including primary care, specialty care and integrated health teams, so that it becomes common practice.

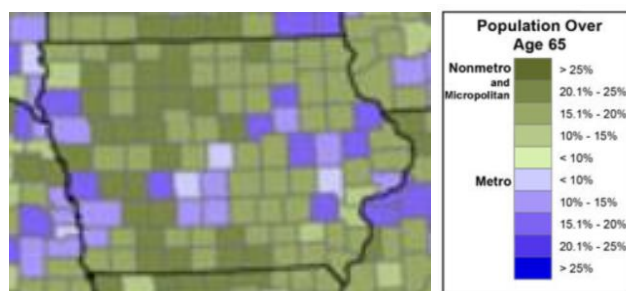
Recommendation 7:

Provide educational resources for primary care, specialty care, integrated health teams and the public to increase the use of advanced care planning and palliative care.

Surveillance and Assessment

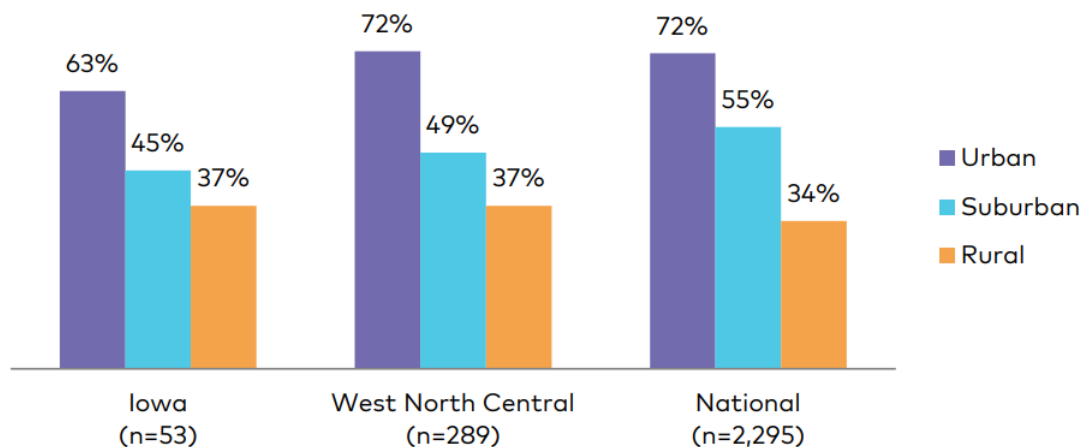
It is important to determine strategies needed to increase access and awareness of palliative care. Initial data are included here which show service gaps, and demonstrate a need for more specific information regarding current numbers of Iowans served by palliative care, areas of limited access, and underserved populations that have difficulty in accessing palliative care. Additionally, many data sources combine hospice and palliative care organizations and providers, necessitating the need for further analysis.

According to 2010 census data, 1,096,099 Iowans lived in rural areas, representing 36 percent of the state population.^{viii} The Rural Health Information Hub used 2010 census data to map Population Over Age 65 by County.^{ix}



The National Palliative Care Registry collects a variety of data on palliative care services and outcomes and produces state level reports. Iowa's 2015 report^x for the National Palliative Care Registry demonstrated that palliative care was less common in rural communities, as seen in Figure 1 below. Nationally, 34 percent of rural hospitals provide palliative care compared to 72 percent of urban hospitals. In Iowa, 37 percent of rural hospitals provide palliative care, compared to 63 percent of urban hospitals.

Figure 1: Percentage of Hospitals with a Palliative Care Program by Community Type



Recommendation 8:

Determine and monitor where palliative care specialty services are available in Iowa, including what specific palliative care services are being provided and identify shortage areas.

Best Practices and Research

National palliative care organizations have compiled tools, resources and best practice guidelines. The council recommends utilizing national guidelines and tools rather than re-creating similar tools in Iowa.

A recommended best practice is to appropriately refer patients to palliative care. Barriers to referral include:^{xi}

- Fear of upsetting patients.
- Not wanting to abandon them.
- Seeing referral as an admission of failure.
- Not understanding the benefits of referral.
- Lack of understanding that palliative care can be provided concurrently with curative medical treatment.

Strategies should be developed to reduce these referral barriers and to promote early referrals. This will ensure palliative care begins early in the course of treatment of the serious medical condition. Reluctance to accept a recommendation to a palliative care specialist on the part of the patient and family can vary from one culture to another, but a common hesitation is the association of palliative care with hospice. Thus, public education and awareness about palliative care is not only important to reduce the confusion of hospice and palliative care, but to enhance quality of care during serious medical conditions.

Recommendation 9:

Increase the recognition and adoption of national tools, resources and best practices in palliative care and advanced care planning.

Recommendation 10:

Identify best practice referral methodologies for providers to refer patients and their families for palliative care specialty services.

Recommendation 11:

Ensure that palliative care and advanced care planning services are culturally and linguistically appropriate and accessible to all.

Reimbursement

Establishing sustainable payment models for palliative care services is an important component to increasing the availability of palliative care and improving quality of life for patients and families. Palliative care can result in significant cost avoidance and savings. As the health care delivery landscape evolves and moves toward value-based care, palliative care reimbursement should be incorporated into these discussions.

Recommendation 12:

Explore and identify reimbursement methodologies in order to integrate and support palliative care and advanced care planning in all appropriate care settings.

Recommendation 13:

Educate healthcare leaders, stakeholders, payers and policymakers on the evidence for improved outcomes and cost-savings from providing palliative care.

The need for palliative care in the state will continue to grow as Iowa's aging population continues to grow.

Workforce Development

Palliative care can help people with a serious illness and their families manage the symptoms of the illness. The need for palliative care in the state will continue to grow as Iowa's aging population continues to grow. It is projected that Iowa's population age 65 and older will grow to constitute 19.9 percent of Iowa's total population by 2050.^{xii} Approximately 80 percent of older adults have at least one chronic disease and 77 percent have at least two.^{xiii}

A robust and widely-available palliative care workforce is essential to delivering high quality, accessible palliative care throughout Iowa. Strategies need to be identified to increase and sustain the palliative care workforce. Collaboration among a variety of organizations across Iowa, including but not limited to educational institutions, health care delivery systems and professional organizations, is essential as strategies are developed.

Recommendation 14:

Identify palliative care workforce gaps and barriers and explore strategies to increase the palliative care workforce, which includes supportive and home-based services.

Recommendation 15:

Identify best practices to encourage and incentivize educational institutions, healthcare delivery systems and professional organizations to increase the number of palliative care specialists in Iowa.

Recommendation 16:

Engage and integrate allied professionals and community services in the collaborative provision of person-centered and palliative care.

Utilization of Advanced Care Planning

Advanced care planning tools such as living wills, advanced directives and the Iowa Physician Orders for Scope of Treatment (IPOST) are important and beneficial tools to communicate the preferences and wishes of individuals. These advanced care planning tools are under the patient's control and provide clear guidance and direction to healthcare professionals, reduce the decision-making burden for family members and ensure that the individual avoids unwanted procedures or treatments.

A living will is a written, legal document that spells out medical treatments that individuals would and would not want to be used to keep them alive, as well as other decisions such as pain management or organ donation.^{xiv}

Advance directives are written, legal instructions regarding preferences for medical care if an individual is unable to make decisions for themselves. Advance directives guide choices for healthcare providers and caregivers if an individual is terminally ill, seriously injured, in a coma, in the late stages of dementia or near the end of life.^{xv}

The IPOST is a double-sided, one-page document that allows a person to communicate their preferences for key life-sustaining treatments including resuscitation, general scope of treatment, artificial nutrition and more. IPOST is appropriate for an individual who is frail, elderly or who has a chronic, critical medical condition or terminal illness. In the last stages of illness, health decisions can be complicated and difficult for the patient, their families and even the treating health providers. IPOST helps health providers guide and support the patient and their families during this sensitive time. A completed IPOST creates a clear declaration of the patient's healthcare treatment choices and assures that the patient's wishes are fulfilled at the prescribed time.^{xvi}

Recommendation 17:

Promote early and routine person-centered advanced care planning across all settings, including family members, caregivers and durable powers of attorney, as appropriate.

Recommendation 18:

Enhance awareness and utilization of methods to document patient care wishes such as living wills, advanced directives and the Iowa Physician Orders for Scope of Treatment (IPOST).

Appendix A: Patient-Centered Health Advisory Council

Patient-Centered Health Advisory Council

The Patient-Centered Health Advisory Council is a legislatively-directed council within the Iowa Department of Public Health (IDPH). The council originated from state legislation that was passed in 2008 in which two separate councils were charged to work on medical homes, and prevention and chronic disease management initiatives. Throughout the years, the councils adapted to the changing healthcare environment to focus on emerging healthcare issues and social determinants of health, and merged into one council called the Patient-Centered Health Advisory Council. The council's website with more information can be accessed at <https://idph.iowa.gov/ohct/advisory-council>.

House File 393 directs the Council to:

- Serve as a resource on emerging healthcare transformation initiatives in Iowa.
- Convene stakeholders in Iowa to streamline efforts that support state-level and community-level integration and focus on reducing fragmentation of the healthcare system.
- Encourage partnerships and synergy between community healthcare partners in the state who are working on new system-level models to provide better healthcare at lower costs by focusing on shifting from volume-based to value-based healthcare.
- Lead discussions on the transformation of the healthcare system to a patient-centered infrastructure that integrates and coordinates services and supports to address social determinants of health and to meet population health goals.
- Provide a venue for education and information gathering for stakeholders and interested parties to learn about emerging healthcare initiatives across the state.
- Develop recommendations for submission to the department related to healthcare transformation issues.

Patient-Centered Health Advisory Council Members

Chris Atchison, MPA
Public Member

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David Carlyle, MD
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Appendix B: Palliative Care Awareness Survey Questions

Palliative Care Awareness Survey
Patient-Centered Health Advisory Council
Iowa Department of Public Health

Palliative care, also known as comfort care, supportive care and symptom management, is specialized medical care for people living with a serious illness. It focuses on managing the symptoms caused by the treatment of the serious illness, such as pain, nausea and fatigue. Palliative care also provides an extra layer of support for practical needs, particularly for care provided at the patient's home. The goal is to improve the quality of life for both the patient and the family.

Palliative care is provided by a team of experts (palliative care physicians, nurses, social workers and others) who work together with the primary specialist treating the patient for their specific illness to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided at the same time as medical treatment.

Please answer the following questions about your current level of awareness of palliative care and the availability of palliative care in Iowa. The answers you provide will be unidentifiable.

1. What best describes you? If you identify with more than one of these options, please choose the one you identify most strongly with, and answer the remaining questions based on that perspective.
 - a. Consumer/Patient
 - b. Family Member/Caretaker
 - c. Health Care Provider
 - i. Working in Palliative Care
 - ii. Not working in Palliative Care
 - d. Health/Social Service Professional
 - e. General Public
 - f. Other: _____
2. Prior to this survey, have you heard of the term "Palliative Care?"
 - a. Yes
 - b. No
 - c. Not Sure
3. How knowledgeable, if at all, are you about palliative care?
 - a. Very knowledgeable
 - b. Knowledgeable
 - c. Somewhat knowledgeable
 - d. Not at all knowledgeable

4. If you or a loved one were to need palliative care, would you know where to access this type of care in Iowa?
 - a. Yes
 - b. No

5. What do you think palliative care tries to achieve? (check all that apply)
 - a. Comfort
 - b. Pain relief
 - c. Dignity
 - d. Care before death
 - e. Peaceful death
 - f. Quality of life
 - g. Support of caregivers
 - h. Not Sure
 - i. Other

6. Where do you think people currently receive palliative care? (check all that apply)
 - a. Hospice
 - b. Hospital
 - c. Own Home
 - d. Nursing Home
 - e. Not Sure
 - f. Other

7. What services do you think palliative care should include or provide? (check all that apply)
 - a. Control of pain and other symptoms at home
 - b. Extra help at home to give family caregivers support
 - c. Medical care in a hospice
 - d. Nursing help at home during the night
 - e. Nursing help at home during the day
 - f. Someone to be available by the phone for support
 - g. Help at home with housework
 - h. Methods of comfort
 - i. Information and advice on financial matters
 - j. Someone to talk about spiritual matters
 - k. Medical care in a hospital
 - l. Alternative therapies such as aromatherapies, reflexology, meditation, acupuncture

8. How likely, if at all, would you be to consider palliative care for yourself and/or a loved one?
 - a. Very likely
 - b. Somewhat likely
 - c. Not Sure- I would need more information
 - d. Not likely at all
 - i. If so, why not? _____

9. If you were to need palliative care, where would you prefer to receive that care? (check all that apply)
- a. Hospice
 - b. Hospital
 - c. Own Home
 - d. Nursing Home
 - e. Combination of care settings
 - f. No Preference
 - g. Other _____
10. Where would you prefer to receive information for you or a loved one if palliative care was needed? (check all that apply)
- a. Primary Care Provider
 - b. Palliative Care Provider
 - c. Health Care Specialist related to Illness
 - d. Health/Social Service Organization
 - e. Close friend/relative who received palliative care
 - f. Newspaper/Magazine
 - g. Television/Radio
 - h. Internet
 - i. Not sure
 - j. Other _____

Resources

- ⁱ <http://www.legis.state.ia.us/legislation/billbook/billResources?action=printOpen&bill=HF%20393&status=e&ga=87>
- ⁱⁱ http://www.patientclientcouncil.hscni.net/uploads/research/Palliative_Care_Executive_Summary.pdf
- ⁱⁱⁱ <https://www.palliativecarescotland.org.uk/content/publications/PublicAwareness-PalliativeCare.pdf>
- ^{iv} <http://getpalliativecare.org/whatis>
- ^v <https://www.capc.org/payers-policy-makers/value-proposition/>
- ^{vi} <https://www.acscan.org/palliative-care-and-improving-quality-life>
- ^{vii} <http://healthaffairs.org/blog/2017/05/19/the-humanity-in-end-of-life-care/>
- ^{viii} http://www2.census.gov/geo/docs/reference/ua/PctUrbanRural_State.xls
- ^{ix} <https://www.ruralhealthinfo.org/topics/aging>
- ^x https://registry.capc.org/wp-content/uploads/2017/08/IA_WestNorthCentral_StateReport.pdf
- ^{xi} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5398324/>
- ^{xii} <https://www.iowaaging.gov/>
- ^{xiii} <https://www.ncoa.org/news/resources-for-reporters/get-the-facts/healthy-aging-facts/>
- ^{xiv} <https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303>
- ^{xv} <http://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303>
- ^{xvi} <http://idph.iowa.gov/ipost>